

## **Factors Associated With Disclosure of Hiv/Aids Status to Hiv Infected Children On Anti Retroviral Therapy (Art)**

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**ABSTRACT:** *Children of today are the youth of tomorrow. HIV status disclosure to HIV/AIDS infected children who are on ART is very essential to maintain the adherence of the treatment for developing the resistance power/protect from opportunistic infections. Parents, care givers and health care professionals are unwilling to inform/disclose children about their HIV status. The main objective of this study is to identify the ratio of children who have known their HIV status and factors associated with disclosure in HIV infected children who are on ART in Andhra Pradesh. A cross-sectional study was conducted in three districts of Andhra Pradesh. The respondents for the study were children living with HIV/AIDS and on Antiretroviral Treatment (ART) and their caregivers in selected ART centres in Andhra Pradesh. A total of 109 children, parents/caregiver pairs were interviewed in the study. 56 children (51.38%) were above 10 years of age. HIV/AIDS status was known by 41 (37.6%) children, 86 (78.9%) caregivers said that the child should be informed about their HIV/AIDS status when he/she complete 14 years of age. 90 (82.57%) of them opted for disclosure of HIV status to child should be done by Health care Provider. Children less than 10 years of age and those living with literate caregivers are less likely to know their results than their counterparts. Children from CCC/Institutions were probably know their results than those from community. The ratio of disclosure of HIV/AIDS status to children on ART is low. Strengthen of ART centres/Health Care providers' skills to motivate the caregivers to increase the rate of disclosure.*

**KEY WORDS:** *HIV/AIDS, ART, ART centres, Caregivers, disclosure of HIV status, Community Care Centre.*

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### **I. INTRODUCTION:**

HIV/AIDS is increasingly affecting the health and wellbeing of children and damage hard-won increases in child survival in some highly affected countries. Recent estimates from the Joint United Nations Programme on HIV/AIDS (UNAIDS) suggest that, globally, about 2.5 million children, younger than 15 years of age are infected with HIV; 90% of whom live in sub-Saharan Africa. In India, it is estimated that 70,000 children below the age of 15 are living with HIV. About 21,000 children are infected every year through parent-to-child transmission. A small proportion are also infected by unsafe injections and infected by blood transfusions. Most children are infected with the virus while still in the womb, during birth or while breastfeeding. The National Pediatric Antiretroviral Treatment (ART) Initiative was launched in 2006 by Government of India. A total of 28,225 children are receiving free ART through 342 ART Centres and 685 Link ART Centres (NACO 2011-12 Annual Report)<sup>1</sup> living with HIV provided ART by the end of NACP-III.

### **II. IMPORTANCE OF THE STUDY:**

As highly active ART becomes increasingly available in low-resource settings, children affected by this disease are living longer, experience a less symptomatic early course of the disease, and survive to older ages, with improved quality of life. Given this scenario, the question of disclosure of HIV status to infected children is becoming increasingly important. Knowledge of HIV status may affect compliance with antiretroviral therapies and influence children's participation in healthcare decision-making. Many health care professionals recommended that knowing the HIV status to the children will leads to better adherence and especially the adolescences, above the age of 14 years, should know their HIV status because there are more venerable to attract the opposite sex. Caregivers and healthcare workers are facing a big challenge to disclose the status to the children who are on ART. Disclosure of a child's HIV/AIDS status is becoming a common clinical issue. However, some parents/caregivers and health care professionals are unwilling to disclose their status. There are some studies conducted in other countries indicates that between 25% and 90% of school-age children with HIV/AIDS infection have not been told that they are infected.

**Definitions:** Disclosure refers to when the caregiver said that the child knows his/her HIV/AIDS diagnosis regardless of who told the child.

### III. REVIEW OF LITERATURE:

There are a few earlier studies related to understand the factors associated with disclosure of HIV/AIDS status to HIV Infected Children on Anti Retroviral Therapy (ART). According to the study by D.Negese<sup>2</sup>, extensively accepted that the rate of disclosure of HIV positive status to children living with HIV/AIDS is low. Caregivers of young children were independently and significantly associated with disclosure of HIV status. HIV clinical Resources, Clinicians and other members of the multidisciplinary team should collaborate with caregivers of HIV-infected children to disclose the diagnosis of HIV to the child in a developmentally appropriate manner.

### IV. METHODOLOGY:

The research design of the study was quantitative and descriptive. The target population was HIV infected children who are on ART, and their parents/caregivers/healthcare providers from Andhra Pradesh who are engaged with the free ART treatment.

**Sampling:** Simple Random Sampling method was adopted. Sample size collected was 109 pairs. Field volunteers present at the district level contributed and collected the questionnaires directly. The sample was selected in three ART centres in each Guntur, East Godavari and West Godavari districts of Andhra Pradesh. The study design was a facility based cross-sectional study. The primary respondents are children who fulfilled the following criteria were included in the study: 1) Receiving continuous antiretroviral therapy for the past 4 months in the selected ART Centres 2) Caregivers who had been counselled and prepared for initiating ART to child. A Structured Interview Schedule was used. The data were collected by the Professional counsellors, who were trained on how to interview caregivers with sensitivity, empathy and without expressing judgment. Interviews were carried out privately in a separate room in the Community Care Centres (CCC). In order to ensure participants' confidentiality, no names or personal identifiers were included in the written questionnaires.

### V. RESULTS AND DISCUSSIONS:

The data (findings) were analyzed to understand the factors associated with disclosure of HIV/AIDS status to HIV Infected Children on Anti Retroviral Therapy (ART) with suitable statistical techniques.

**Findings:** Socio-economic and demographic profile of the respondents: The descriptive analysis of demographic profile of the respondents shows that, majority (51.4%) of the children fall under the age group of above 10 years. A high (53.2%) proposition of them are female children (Table 1).

**Table 1: Child Profile**

		Age of Child				Chi-square value	p-value
		<10 Yrs		> 10 Yrs			
		N	%	N	%		
Gender	Male	36	33	15	13.8	18.510**	0.00
	Female	17	15.6	41	37.6		
Did child know his/her HIV status	Yes	7	6.4	34	31.2	26.188**	0.00
	No	46	42.2	22	20		

Further, the Table 1 presents as 37.6% of the children does knew their HIV/AIDS status; Even this awareness is observed as highly (32.2%) among male children compare to that of female children. Both the findings that the awareness and sex (gender) does have significant association with the age of the child.

**Table 2: Caregivers profile**

		Gender				Chi-square value	p-value
		Male		Female			
		N	%	N	%		
Marital Status	Single	1	90.0	0	0	28.435**	0.00
	Married	10	9.2	39	35.8		
	Divorced	21	19.3	5	4.60		
	Widowed	19	17.4	14	12.8		
Relation with child	Mother/Father	34	31.2	1	9.0	68.039**	0.00
	Grand F/M	0	0	21	19.3		
	Uncle/Aunt	6	5.5	1	9.0		
	Others/CCC	11	10.1	35	32.1		
Religion	Hindu	12	11	32	29.4	11.459**	0.00
	Muslim	2	1.8	2	1.8		
	Christian	37	33.9	24	22		

Caregivers and healthcare workers are facing a big challenge to disclose the status to the children who are on ART. Care givers demographic profile does has influence on care of the infected child in many aspects. Here in the present study, 35.8% of the caregivers were married and living with their spouse. This indicates that the child is taken care by the family. About 32% of the children are taken care by the community care centres, i.e., Institutional care provided by the Voluntary Organizations. The highest (29.4%) proportion of the care givers among women belong to Hindu religion. Whereas, it is the highest (33.9%) among male caregivers in Christian Community (Table 2). From the table 2 it is also observed that high proportion (31%) of male children are taken care by their parents only. But more girl children were taken care by Community Care Centres.

**Table 3: Caregivers Economical Status versus Marital Status**

Marital Status		Economical Status				Chi-square value	p-value
		BPL		APL			
		N	%	N	%		
Single		32	29.4	17	15.6	13.153**	0.00
Married		1	0.9	0	0		
Divorced		6	5.5	20	18.3		
Widowed		16	14.7	17	15.6		

It is assumed that the economic status of a caregiver does have impact on care giving fashion to the infected children who are On ART. The same is disclosed from the table.3. Here in this study also. In addition, this table shows that even among poor (BPL), the care is observed more among single and widowed (marital status) which is statically significant.

**Table 4:**

		Caregiver's Educational Status				Chi-square value	p-value
		Ill-literate		Literate			
		N	%	N	%		
Did child know his/her HIV status	Yes	20	18.3	21	19.3	.859*	.354
	No	27	24.8	41	37.6		
Preferred age of disclosure by the CG	<10 Yrs	10	9.2	13	11.9	.002*	.969

	>10 Yrs	37	33.9	49	45		
who do you think would be the person responsible for disclosure of HIV status	Parents/ Care Givers/ Family	3	2.8	16	14.7	7.008**	.008
	Healthcare providers	44	40.4	46	42.2		

As is well known, educational status does have a positive and constructive impact on any activity of one's. Here in this study also caregivers educational status is analysed with that of certain characteristics of 'discloser' informing the HIV status to the infected children who are On ART Treatment. Majority of children knew about their HIV/AIDS status who are under the care of Educated caregivers (Table.4). Similarly, about 80% (the highest) of the caregivers in this study expressed that 'disclosure' could be done only to the children above 10 years of child age. Further, about 83% of the caregivers have expressed/suggested/preferred that the process of 'discloser' could be done through health care providers i.e., Counsellors/Doctors/Nurses.

### VI. CONCLUSION:

The rate of disclosure of children HIV positive status among children on ART was low. To increase disclosure rate, it is important to educate caregivers. Intensified information education and communication to de-stigmatize the disease might have far reaching impact. Caregivers and health care providers should have a co-responsibility to settle on the proper time to disclose. Finally, if more information is known regarding HIV infection in children and young adults who would become sexually active and who might potentially engage in high risk behaviour for HIV infection and other sexually transmitted diseases, may be used in constructive or destructive manner.

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